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Care of dying patients in hospital

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Abstract

Objective—To study the process of care of dying patients in general hospitals.

Design—Non-participant observer (MM) carried out regular periods of continuous comprehensive observation in wards where there were dying patients, recording the quantity and quality of care given. Observations were made in 1983.

Setting—13 wards (six surgical, six medical, and one specialist unit) in four large teaching hospitals (bed capacity 504-796) in west of Scotland.

Subjects—50 dying patients (29 female, 21 male) with mean age of 66 (range 40-89); 29 were dying from cancer and 21 from non-malignant disease.

Results—Final period of hospitalisation ranged from 6 hours to 24 weeks. More than half of all patients retained consciousness until shortly before death. Basic interventions to maintain patients' comfort were often not provided: oral hygiene was often poor, thirst remained unquenched, and little assistance was given to encourage eating. Contact between nurses and the dying patients was minimal; distancing and isolation of patients by most medical and nursing staff were evident; this isolation increased as death approached.

Conclusions—Care of many of the dying patients observed in these hospitals was poor. We need to identify and implement practical steps to facilitate high quality care of the dying. Much can be learned from the hospice movement, but such knowledge and skills must be replicated in all settings.

Introduction

Though most terminally ill patients indicate a preference to die at home,¹⁻⁴ national statistics show that in the past two decades more than 60% of all deaths occurred in an institution.⁵ Most of these deaths were in general hospitals.^{5,6}

Several retrospective studies have attempted to assess the level of satisfaction with care in hospital during the final stage of life by means of the recollections of relatives or close associates.⁷⁻¹³ The findings indicate that, despite general satisfaction with the medical treatment, there is evidence of deficiencies in the service, including inadequate control of symptoms

and failure to meet the physical, social, and emotional needs of the patients. More recent surveys have highlighted the distress experienced by patients and their families.¹⁴⁻¹⁶

Few studies have reported systematically collected data on the process of care in hospitals.^{17,18} This descriptive, exploratory study goes some way to redress this. The aims were to describe the nursing care of patients during the final six days in hospital and to identify factors that might influence that care.

Methods

The study was conducted in four large teaching hospitals (bed capacity 504-796) in the west of Scotland, the data being collected during 1983. It was not prepared for publication earlier because of the untimely death of both academic supervisors and the appointment of the first author to a post in the Far East. Permission for access was given by the area health board and by the senior medical and nursing committee of each hospital. Investigations were carried out in 13 wards—six surgical, six medical, and one specialist unit.

Initially, interactions were monitored between 23 dying patients and 190 nurses (48 qualified and 142 unqualified). Notes were made of which nurses attended each patient, the care given, and the length of the interaction. Secondly, 91 ward rounds were attended; the content and length of the consultation between 14 consultants and a further 27 dying patients were noted. Communications between the consultants and 22 senior nurses concerning the dying patients were also noted, ward report sessions were attended, and nursing reports and clinical records were read.

The senior nursing officers in each hospital identified wards in which the criteria for the study were met (that is, an acute general ward where there were patients with varied nursing needs including a patient who was expected to die within six days). All nursing staff were informed that interactions between nurses and the dying patient were being monitored. An approach was made to the consultants for permission to attend the ward rounds, the reason given being to elicit factors that might influence nurses during their care of

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the dying patient, including the influence of the doctor.

As a non-participant observer, one of us (MM) started regular periods of continuous comprehensive observations as soon as a ward met the selection criteria: these continued from 7 30 am—1 00 pm and 5 00 pm—9 00 pm for four days or until the death of the patient. The underlying premise for this tactic was that nursing should be observed amid the stresses and strains of the ward, so that the sociocontextual factors that might affect nurses' behaviour could be noted. The findings are illustrated by case reports describing the care of individual patients.

Results

The mean age of the dying patients (29 women and 21 men) observed was 66 years (range 40–89). Twenty nine patients were dying from cancer and 21 from non-malignant disease. Thirty five patients had not been expected to die during hospitalisation, but when recovery seemed impossible and death inevitable active medical intervention was modified for 33 of these. Two patients received aggressive interventions until death. Fifteen patients were admitted to die. The final period of hospitalisation ranged from six hours to 24 weeks. More than half of all the patients (29) retained consciousness until shortly before death.

INTERACTIONS BETWEEN NURSES AND PATIENTS

The ratio of qualified to unqualified nursing staff was 1:3. This was not reflected in the proportion of time the qualified nurses spent with the dying patients. Two of the 23 dying patients observed initially were not seen to have any contact with a qualified nurse, and 16 had only minimal contact (interactions lasting less than 60 seconds). Nursing care was provided predominantly by junior nursing staff, but the dying

Symptoms experienced by 50 dying patients

Symptom	No of patients
Pain	34
Anorexia	30
Dehydration	28
Dyspnoea	26
Anxiety	20
Pressure sores	19
Depression	15
Faecal incontinence	13
Nausea or vomiting	10
Confusion or disorientation	4
Urinary incontinence	3
Dysphagia	2

Case report 1

A 51 year old woman suffering from breast carcinoma with metastases was admitted to die. She was unconscious, and her breathing was rapid and noisy.

At 8 20 am she was moved into a side room, and two nurses attended to her for nine minutes. They then left the room leaving the door open. At 9 16 am the sister entered the room and checked the charts at the foot of the bed.

At 9 20 am the patient's breathing stopped. Twenty minutes later the ward team (senior registrar, resident, and sister) entered the room. They checked the charts, reviewed the intravenous regimen, and then left the room.

At 9 45 am the sister re-entered and changed the infusion unit as instructed. She was about to leave the room when she glanced at the patient. The screens were drawn immediately, and the door was closed. Death was certified as having occurred at 9 45 am.

Case report 2

A 69 year old woman suffering from carcinoma of the sigmoid colon was admitted to die. She was responsive and lay on her side, breathing quietly with her eyes closed, in the centre of an open ward. At 10 15 am a large stain appeared on her pillow: the patient had stopped breathing.

At 10 30 her elderly husband arrived and was observed asking permission to enter the ward to visit his wife. At this point the non-participant role of the observer was abandoned, and the elderly man was diverted. When told by the ward sister of his wife's death he expressed a preference not to see her body and left.

Case report 3

A 56 year old man was admitted to die. He looked dishevelled, neglected, and miserable. He was seen to smooth his hair with his hand and feel his rough skin. He received no attention to oral hygiene, bathing, or care of pressure areas during two days of observation. The nurses responsible for his care noted that the tasks had been done, though in fact he had received no attention.

Case report 4

A 52 year old woman had metastatic spread involving the liver. She had gross abdominal distension, was icteric and very breathless, but was alert. Her conjunctiva were swollen and she shed icteric tears.

The patient received no care from the nurses delegated to give care. Yet in the nursing kardex it was recorded that attention had been given to her personal hygiene, pressure areas, oral hygiene, and eyes. This was inaccurate: her only attention had been to receive a commode from a nursing assistant. Contact time totalled six minutes in 4.5 hours of observation.

patients were usually alone: eight of the 23 were alone for at least 90% of the observation period, and all but one of the 23 patients were alone for at least three quarters of the time. As the time of death approached their isolation increased (see case reports 1 and 2).

The dying patients had many symptoms (see table). Two thirds of the patients did not receive adequate nursing care in accordance with the standards accepted by the Scottish health department¹⁹ (for example, see case reports 3 and 4). The oral hygiene of 82% of the patients was poor: 56% had no attention given to this need. No consideration was given to the existence of anorexia or nausea, and the food provided was similar to that given to an average hospital patient. The nurses were heard at meal times to suggest that the patients "should try a little," but they did not stay to help. Thirst was not quenched for 56% of patients: the patients were often too weak to drink unaided (for example, see case reports 5 and 6). By contrast, the patients' physical state was recorded regularly—the temperature and pulse of 84% of the patients and the blood pressure of 48% were recorded until death.

WARD ROUNDS

Certain consultants (4/14) and senior nurses (7/22) were seen to have a greater number of encounters and longer contact times with the dying patients. They also showed characteristics that identified them as "caring" people: for example, they spent time with a patient, addressed the patient by name, established eye contact, touched the patient, and asked open ended questions and waited for an answer.

During ward rounds the four "caring" consultants conducted comprehensive consultations and showed a holistic approach to care. Attention was paid to both the physical and psychosocial needs of the patients. Nursing problems were identified, and, after discussion with the senior nurse, precise guidance was given on appropriate measures to provide comfort. The response of the patients to these interventions was reviewed and updated at each visit, and these consultants maintained contact with the patients until death.

The remaining 10 consultants concentrated on the patients' disease, the physical deterioration of the patients, and the attempted relief of some related symptoms. No reference was made to the patients' psychosocial needs apart from ensuring that their relatives had been seen. There was minimal or no personal contact with the patients. The time that these

consultants spent at a patient's bedside was dependent on the continuation of active medical intervention. When active medical intervention was scaled down and death was imminent they withdrew from the patient, either remaining at the foot of the bed or passing the patient's bed without comment or with a brief aside to those in attendance such as "no change?" or "still there?"

A pattern of behaviour by the senior nurses was also noted. Three of the seven senior nurses who were identified as carers also acted as advocates for patients by outlining to the consultants aspects of need that required a medical input. These nurses were persistent until medical intervention gave adequate relief. This contrasted with the actions of their colleagues who

introduced no aspects of patient care for discussion with the consultants but referred only to the recordings of the patients' vital signs.

When both the consultant and senior nurse in a ward team showed caring characteristics the dying patient had more contact time and more attention from qualified nurses and received an acceptable standard of care. Teams in which the consultant withdrew from the patient and the senior nurse had a similar tendency showed a corresponding deficit in patient care. In these circumstances the care of dying patients, by default, became the responsibility of the junior nurse or an unqualified nursing assistant.

Case report 5

A 57 year old woman was weak but alert. She lay sleeping but was roused by a nurse to have her temperature and pulse recorded. "Can I have a drink?" she asked.

"I'll be back in a few minutes," said the nurse.

Fifteen minutes later a porter passed: "Eh mister, can I have some water please?" she asked. He smiled and passed on.

Ten minutes later a doctor passed: "Doctor, water please," she said.

He looked over, approached a nurse who was attending another patient, and then returned and said, "It's coming."

Five minutes later the patient called out desperately, "Listen, a glass of water, please. All I want is water. I'm choking for water, cold water." At this point a nurse approached and offered the patient a drink. She took the glass and slowly drank the water.

Case report 6

A 41 year old woman was dying from hepatic carcinoma. She had extensive abdominal distension. Her breathing was further complicated by her congenital deformities of a kyphosis and barrel chest. She was alert and was experiencing severe thirst.

At 5 25 pm a supper tray was placed before her, and she was lifted to the side of the bed and placed unsupported with her legs dangling over the side. Being unable to support herself, she fell back.

At 5 42 a cup of tea was placed on the tray. She struggled to reach the tea but was unable to do so. "Did you have a drink?" asked a nurse. There was no response and "120 cc tea" was recorded on the fluid balance chart.

At 5 50 pm the patient tried to reach a drink on her locker without success. At 6 05 pm she rolled over, drew in her legs, and tried to cover herself with her sheet.

At 6 10 pm the tray was removed with the food untouched; no contact was made with the patient. At 6 50 pm a member of staff placed a glass of water on the locker; there was again no contact.

Visitors attended the patient between 7 00 and 8 00 pm.

At 8 15 pm a nurse approached and asked the patient if she would like tea or coffee. "I've got juice," she replied. She tried to raise herself to reach the drink on her locker, but it was beyond her reach. She struggled but eventually lay back exhausted. She continued this struggle for half an hour, moaning as the nurses passed, and then called out at 9 20 pm to a nurse.

"What's wrong?" asked the nurse. The patient indicated that she wanted her juice. The nurse handed the patient her juice and then left (nine seconds contact). The patient attempted to drink, but could not keep her head up to do so. She could neither drink the juice nor lay the glass down on the locker, which was beyond her reach. She looked once more in the direction of the observer. Observations were discontinued, and the patient was helped to drink.

Discussion

"There is no better way to obtain data to describe a set of behaviours than to watch the persons behaving."²⁰ This observational study revealed that not only was there inadequate control of symptoms in dying patients but also that there was inadequate nursing care and minimal attention from most senior medical and nursing staff. Although these data were collected 10 years ago, current evidence suggests that the findings are still relevant to current practice. The findings on control of symptoms are in line with many other studies, which consistently show that terminally ill patients suffer severe and unrelieved symptoms^{3 6 11 14} increasing in severity and frequency as death approaches.^{14 21 22} Yet experiences in hospices and centres for palliative care indicate that it is possible to achieve good control of pain in about 95% of patients.^{23 24} Other symptoms may be complex and sometimes difficult to control, but they also respond well to a concerted approach.²⁵ Adequate assessment and continuing monitoring are essential to achieve optimum relief.^{24 26}

NEED FOR A HOLISTIC APPROACH

Appropriate care of dying patients requires attention to all of the patients' needs,²⁶ a vital component of which is nursing care. Care and cleansing of the skin, constant care of the mouth, and the provision of adequate fluids and appropriate well presented food are all part of this care. These basic nursing interventions to maintain patient comfort were often not provided for most of the patients observed in this study.

Care extends beyond attention to physical needs: alleviation of individual patients' emotional, social, and spiritual problems should also be an integral part of their care.²⁶ This requires that time be spent with patients to identify their needs. This requires a commitment to and a personal interest in the patients.^{18 27} As in other studies,²⁸ this was rarely observed: contact between nurses and the dying patients was minimal; and distancing and isolation of patients were evident, the isolation increasing as death approached.

Most of the consultants concentrated on the disorder rather than the person with the disease. Most senior nurses mimicked this behaviour by concentrating solely on the recordings of vital signs. For many patients there was little or no reference made to their specific physical problems or psychosocial needs. This threw into sharp focus the small group of senior medical and nursing staff who took time to be with the patient and who could be identified as carers by their attention to personal rather than technical matters. They identified all the needs of the person who was dying, explored various ways to give comfort, and initiated medical and nursing measures to provide relief.

REASONS FOR INADEQUATE CARE

It is important to realise that most medical and nursing staff are motivated to provide quality care:

Clinical implications

- More than half of terminally ill patients in Britain die in an institution, most in a general hospital
- Studies have suggested that the care of dying patients in hospital is inadequate
- Observations of 50 dying patients in four large hospitals showed that patients' symptoms were not adequately controlled and many received inadequate nursing care
- Patients received only minimal attention from most senior medical and nursing staff, their oral hygiene was often poor, their thirst remained unquenched, and they were given little encouragement to eat
- The skills developed in hospices must be learnt in hospitals if terminally ill patients are to die with minimal discomfort

there are many factors beyond their control that cause the care of dying patients to be less than adequate. These include lack of professional education,^{12 15 29} busyness,¹¹ an inappropriate ward environment,¹⁷ modern monetary and technological issues,³⁰ and tactics adopted by carers to avoid contact with dying patients.^{28 29 31} Distancing tactics are a natural reaction of medical and nursing staff "to prevent them getting too close to the patient's psychological suffering... to try to ensure their own emotional survival."³¹ The outstanding question is how these attitudes and behaviours can be changed to benefit patients while simultaneously protecting carers. Creating a climate conducive to the practice of caring skills is essential, as is justifying time spent with a patient during the final stage of living. A recent paper describes some appropriate mechanisms for improving the quality of care of dying patients.³²

CONCLUSION

In general hospitals medical care is concentrated on arresting disease and on recovery and rehabilitation. When death is inevitable palliative care must take priority over curative care. Our study suggests that this often does not happen. Yet dying patients are an integral part of the population of general hospitals. Their death should not be considered a failure; the only failure is if a person's death is not as comfortable as possible.

Only the forbearance of the patients who were dying and those close to them made this study possible. MM is grateful to them and to the staff in the clinical areas for their assistance and tolerance. Huw Davies is currently supported by the Clinical Resource and Audit Group (grant No CA 91/4) and has received much assistance from the North British Pain Association. Their support is gratefully acknowledged, but

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A BOOK THAT CHANGED MY LIFE

The appeal of surgery

There is something beautiful, intimate, and simple about surgery. The book that my brother gave me for my 21st birthday says all this with a meandering poetic style. In *Confessions of a Knife* Richard Selzer describes the strengths of individual patients he has treated and his own struggles for perfection in the operating theatre.

The book appealed to my holistic ideals. The concept of supporting people to take control of their own health seemed to fit in perfectly with my becoming the kind of doctor that just sorted out a mechanical problem in the way that surgery can. It is good when you find a book or a soulmate who verbalises what you have only thought. All other doctors thought that I was mad.

There was another reason why people thought I was mad: anyone hearing that I wanted to be a surgeon would

tell me how difficult it was for women. At my interview at Cambridge I was asked if I knew that there were only nine women consultants in general surgery in the country. I expect everyone was trying to be kind. I got no advice and no support. I began to think that I might have been wrong in thinking that surgery would be fun in the exhilarating, perfectionist way that Richard Selzer describes.

Seven years ago something gave me the confidence to stop the negative feedback. I like to think that it was this book, which I now see as wildly pretentious, that showed me that you have to be a human being to be a surgeon, not necessarily a man.—SCARLETT HUTCHINSON is a senior house officer in plastic surgery in East Grinstead

Selzer R. *Confessions of a knife*. London: Triad/Granada, 1982.